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ABSTRACT

This handbook offers guidance to parents and staff in developing day care programs which include handicapped children. In Section 1 of the handbook, terms commonly used to describe disabilities are defined. Section 2 presents a picture of the current situation in New York City regarding attitudes toward handicapped children and options for their education. The basic issues to be faced by any day care center wishing to integrate handicapped children into existing programs are discussed in Section 3. Existing integrated and specialized programs, city agencies concerned with education of the handicapped, and additional community resources in New York City are identified in Section 4; and funding sources for programs for young handicapped children in the New York City area are described in Section 5. Two brief papers found in Section 6 provide personal accounts of experiences in integrated and specialized day care programs. (ED)

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HANDICAPPED CHILDREN

AND DAY CARE

Ruth Barngrove Sauer

Day Care Consultation Service
Bank Street College of Education
610 West 112th Street
New York, New York 10025
(212) 663-7200

March 1975

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HANDICAPPED CHILDREN

AND DAY CARE

BY

Ruth Barngrove Sauer

Revised and Updated Second Edition

The Day Care Consultation Service
Division of Field Services and Leadership Development

Bank Street College of Education
New York, N.Y. 10025

(212) 663-7200

Revised and Updated Second Edition

The first edition of this handbook was prepared as a supplement to the "Manual: on Organization, Financing and Administration of Day Care Centers" * and published by the Bank Street Day Care Consultation Service in 1973.

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* Manual: on Organization, Financing and Administration of Day Care Centers in New York City for Community Groups, their Lawyers and Other Advisors, 2nd Edition.

Bank Street Day Care Consultation Service

515 pages: $5.50 plus $ .75 postage and handling.

Although the Manual was written specifically for New York City groups, it contains information which groups outside of New York City may find helpful. For example, the Manual has sections on bookkeeping, health programs, by-laws, staffing, curriculum, and staff training. It is available from the Bookstore, Bank Street College of Education, 610 West 112th Street, New York City 10025.

General Introduction To This Handbook

This handbook is written to be used by parents and staff of day care centers in the New York City area who want to include handicapped children in preschool programs.

One way for non-handicapped and handicapped children to come together is through a neighborhood day care center. If this is to happen, the parents and staff from the centers must become familiar with the prejudices, problems and possibilities involved in running a program with handicapped children.

In this handbook we will bring out some of the questions staff and parents will have as they develop a supportive program for handicapped children and their families. Some issues are raised in this booklet which you must question and think about. Please comment to us on all parts of this booklet. We want to continue to provide information that will be useful and thought-provoking.

Throughout this handbook you will see we have a definite point of view. We believe it is important and necessary that children with handicaps be educated with children who are not handicapped. We believe it is essential to bring children who have no handicaps together with those who have them. This early contact will benefit all by breaking down many barriers and prejudices present in our society today.

We wrote this handbook to help you bring together <u>all children</u> in your centers. This handbook can help you find ways to do it.

We wish to thank the many people who contributed to this handbook. It is not possible to list here all the individuals we talked with, but those we thank especially are: Susan Baitler, Dorothy Broms, Day Care Consultation Service staff, Scott Fitzgerald, Pat Greenwald, Teddy DeSoyza and "These Our Treasures," and Roz Williams.

Ruth B. Sauer

Ruth and Peter Sauer are parents of three children. One is a handicapped child, Hannah, born with Down's Syndrome, on November 18, 1965.

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Section 1

UNDERSTANDING DISABILITIES

I. Introductory Remarks 1.1

II. Disability: Handicap.....1.2

III. Development and Disabilities.....1.3

IV. Glossary of Terms.....1.10

V. Slang -- Not to be Used.....1.14

VI. Bibliography.....1.16

This section was researched and prepared by Susan Baitler, teacher of children with disabilities, and currently employed at the Bronx Developmental Services. She has been working with HeadStart Programs on the integration of young children.

UNDERSTANDING DISABILITIES

1. INTRODUCTORY REMARKS:

While this handbook talks specifically about children who have disabilities/handicaps, it is important to keep in mind that we are emphasizing helping children who have obvious differences in development rather than singling them out and isolating them because of these differences.

It is important, we believe, to see a child as completely as possible and this means the handicapped child, too. But if you are like many of us who have had no previous personal experience with a child who has disabilities, it will be difficult to see the child over those specific disabilities.

We believe that you can begin to see that child if you become more familiar with, and eventually at ease with, the various specific handicaps or disabilities a person may have. In fact, your own knowledge about and familiarity with the terms and descriptions of the particular disabilities will help you develop less fear of and less awkwardness around a child or adult who has them. All the better -- you as a more educated, aware person will be able to reach out to and become involved with that young child. Your involvement with her will help her play. You will instruct her and help her grow in spite of her disability.

Please read this next part to begin your involvement, to begin to learn and become familiar with some of the more commonly-used terms and descriptions that refer to disabled people.

II. DISABILITY: HANDICAP: What do they mean?

The terms disability and handicap are commonly used interchangeably. That's okay for common usage. However, the difference between them and its implications on people and their lives provide important food for thought here. A person is thought to have a DISABILITY when he is lacking or has lost a tool or an ability that is considered valued in the world in which he lives. A disability could be the loss of the ability to see, the ability to hear, or the loss of movement of ones' limbs. A person may be thought of as HANDICAPPED when her lack of a specific tool or ability prevents her from "functioning" in the society in which she lives. A person with a disability does not have to be handicapped when there is training and care which emphasize her/his own specific abilities and builds these abilities into strengths.

Some people feel that the word handicapped is negative in tone and insulting. These people believe it focuses on the weaknesses and limitations of human beings. These people prefer the word disabled. They feel that word brings to mind the specific part or ability that does not work -- the "disabled arm" rather than "the crippled person." In other words, it is not the person who does not function but the arm which cannot move (to lift or grasp, for example.)

Furthermore, handicap has been associated historically with some awful words: "defective," "backward," "maimed," "moron,"

"deformed," "insane." We can easily see that those words are objectionable and should not consciously be used today. Often less distasteful terms "exceptional children," "special children," "children with special needs" -- are used to make the image of a "handicapped" person less ugly. We are not implying that it is inappropriate to use these terms. Yet, they could be misleading if they cloud or mask the real problems which do exist where a disabled person is concerned.

We hope people will think about the words they use as they reflect our attitudes and feelings about others. We are advocating using a language and having an awareness that is humane, realistic, and sincere.

III. DEVELOPMENT AND DISABILITIES:

All children grow and develop at their own rate. They all develop:

- language or communication skills to enable them to express themselves,
- large and small muscle skills to move through and manipulate the environment,
- social and emotional skills to deal with people, situations, and feelings,
- conceptual skills to deal with thoughts, relationships, and qualities of things in the environment,
- self-care skills to deal with dressing, grooming, toileting, and feeding.

Every child moves toward development in these areas. Yet, no two children move at the same speed; one child may develop faster in one area than in another. These are the individual differences we expect.

For some children, development in one or more of these areas may be particularly difficult. These children may have specific disabilities. In trying to give such a child the most assistance possible to learn and grow, you may wonder why he has this difficulty. To help you understand this difficulty we have grouped the disabilities into the following possible areas:

1) Medical handicaps or disabilities.
2) Physical handicaps or disabilities.
3) Sensory disabilities; sensory impairment.
4) Emotional disturbances or disabilities.
5) Multiple handicaps or disabilities.
6) Neurological impairment.

This is our way of putting them into some kind of general groups. This does not represent the only way to think about them. These descriptions can be a good beginning which your staff and parents can broaden through their own experiences and by reading. (See our Bibliography at the end of Section 1.)

1) MEDICAL HANDICAP OR DISABILITY is any condition that affects a person's health and usually requires some treatment or supervision by a medical doctor. A child with a medical disability can attend a day care center as long as an adult is aware of the prescribed treatment. This may be following a special diet, or limiting physical activities.
   Examples are: Epilepsy, heart condition, diabetes, asthma, sickle cell anemia.

2) PHYSICAL HANDICAP OR DISABILITY is caused by accident, birth injury, severe illness which damages part of the body and prevents it from functioning normally. Some physical disabilities are mild and some are severe. A physically handicapped person may use crutches, walkers or wheelchair, braces or artificial limb. Physical therapy may help, too. Remember, a physically handicapped person does not necessarily have impaired intelligence.

Examples are: A child born with missing fingers; a child with bowed-legs; a child with paralysis.

3) SENSORY DISABILITY, SENSORY IMPAIRMENT is damage to any part of the human body relating to our "senses" - taste, touch, sight, hearing, smell.

Examples are: loss of ability to feel pain, hot or cold; inability to differentiate between color; color blindness; inability to hear sounds.

4) EMOTIONAL DISTURBANCE - Some of the characteristics of a person with emotional disturbance are: having difficulty tolerating frustration, noises, or a change in activities; being easily distracted; having severe withdrawal so that the child appears to have built a wall around him and won't let you in; being extremely fearful at an age where these fears are no longer appropriate; not making eye contact with another person; having severe out-bursts of noise and activity which may include head-banging or bizarre sounds when none of this is appropriate behavior. Generally, the person cannot cope with everyday living.

CAUTION HERE: Often a young child shows some of these symptoms when sad or troubled. He may be confronted with inability to understand the language spoken in the center; shyness in a new situation; feeling frustrated in a new situation or with new materials. These few characteristics are NOT enough to place a "disturbed" label on the child. You must check out all parts of the child's present life situation to see how the whole child acts in order to figure out what temporary condition may be troubling him and to know where to get help, if needed.

5) MULTIPLE DISABILITY, MULTI-HANDICAPPED refers to a person who has more than one of the disabling conditions we describe in this section. A child with a multiple disability may need treatment or help from more than one source.

Examples are: children who are both blind and deaf or physically handicapped and deaf.

6) NEUROLOGICAL IMPAIRMENT - occurs when there is damage to or poor development of, the central nervous system, (the brain, nerves, and spinal cord.) This damage can cause:

a) Cerebral Palsy: refers to the inability to control muscles normally as a result of poor development or injury to the brain. The injury can occur before, during or after birth and can range from mild to severe. There are different kinds of cerebral palsy depending on the type of muscular problems which result from the injury to the brain. Those described as having spastic cerebral palsy tend to have stiff, rigid movements. A child with athetosis will be unable to control her muscles from making involuntary movements. It may be very difficult for her to talk or move without the muscles of her face or body moving uncontrollably. One with ataxic cerebral palsy has difficulty with balance. Often, children with cerebral palsy can be helped to control their movements better with training and physical, occupational and/or speech therapy.

People who have cerebral palsy frequently have other disabilities as well. Yet, not all are impaired intellectually. Many have become lawyers, writers, teachers as well as going on to other forms of productive adulthood in spite of their disability.

b) Epilepsy: a condition caused by poor development or injury to the central nervous system before, during or after birth which results in repeated "seizures." Seizures can be thought of as storms of uncontrolled or unchanneled electrical discharges in the brain. Seizures can vary in form and intensity -- some are very obvious and others are hardly noticeable.

Two types of seizures often referred to are commonly called "petit mal" and "grand mal." During a petit mal seizure, a person may very briefly lose attention to what he was doing; may stare off into space blankly for a few moments; may blink his eyes

rapidly and drop something he had been holding. This type of seizure is brief and can occur many times each day. Once the seizure is over, the person usually goes right on to what he was doing before. A grand mal seizure looks quite different. It involves a temporary loss of muscle control with strong shaking of the entire body and loss of consciousness. When the seizure is over, many people require undisturbed sleep. Awake again, the child or adult may be somewhat tired but frequently returns to previous activity. Some people experience a warning signal or sensation called an "aura." Moments before a grand mal seizure will occur, they may be aware of a particular sound, taste, odor, or feeling. This warning can enable a child in your center to find a safe, protected corner where he can lie down until the seizure is over. Often seizures can be kept under control with medication. It is important to communicate any changes in behavior or seizure control to the child's parent and doctor. Since there are a variety of drugs available to control epilepsy and everyone responds differently to these, the child's doctor may need your help in observing the child to determine an effective prescription.

People with epilepsy - children with epilepsy - vary in intelligence just like all people. They can attend your center, go to school and hold productive jobs. However, most of us have been brought up with vestiges of "old myths of demons and evil spirits" concerning epilepsy which fills even well-meaning adult minds with prejudice, distorted ideas, and unnecessary fear. Such prejudice and fear can be a more devastating handicap than the epilepsy to parents trying to find day care for their child. Don't let this happen in your center!

c) Mental Retardation: people with mental retardation are intellectually handicapped. A person with mental retardation may have difficulty abstracting thoughts or ideas, learning complicated problems, or carrying one idea into the next. It is characterized by an overall slowness in many areas of development (language, muscle control, social development, intelligence, for example.) Frequently a person with mental retardation may also have physical, medical, sensory, and/or emotional disabilities.

Mental retardation can be caused by certain severe childhood illnesses; by eating lead paint or plaster chips; by genetic factors; by severe accident or injury to the nervous system; by certain drugs; and by severe malnutrition. These factors affect the development of the central nervous system. As with all disabilities, mental retardation varies in degree from mild to severe. For some people, the disability may make school work difficult. These people can learn to do a single job and be somewhat independent. For others, independent living may not be a reality; they may need assistance in feeding, dressing, and all of everyday life. MR is no longer thought of as a "disease" -- with no cure -- but a condition of living which does respond to training.

Traditionally, the term mental retardation has had negative implications, always describing behavior by including "not able to" -- "a retarded person is not able to speak clearly, is not able to be independent, etc." It is important to grow familiar with some of the things retarded children can do when they have training and education; such as learning to communicate, learning to cooperate and get along with other people; learning to care for their personal needs as independently as possible.

d) Minimal Brain Dysfunction - is a generally accepted medical term used to describe a child who is of average or above average intelligence, and who displays learning and behavior difficulties associated with neurological impairment. This is a difficult disability to define. These are children who appear alert, curious, intelligent but do have trouble learning some things. They have been referred to as "brain injured, perceptually handicapped, neurologically handicapped, and dyslexic." Sometimes, the overall condition may be referred to by the term "learning disability."

A child with MBD developes unevenly. He may be awkward or immature in some areas of his development -- in motor area, for example, an eight year old may be unable to skip, look clumsy while running, may have trouble buttoning clothing or using a pair of scissors; yet he may be way ahead -- in the language area, for instance. This child might be described as hyperactive, distractible, impulsive; perseverating (repeating the same action or question over and over again inappropriately); irritable; and as having a

short attention span. All of the characteristics described here could be noticed in most children at some age. However, when these characteristics persist far beyond the age when such behavior is appropriate and when they are observed along with perceptual-learning-problems, we may suspect that a child could have Minimal Brain Dysfunction.

In addition to a child's behavior she may show difficulty in perception. Her hearing and vision may be fine -- yet she has difficulty putting together what she hears and sees to mean something useful to her. Because she has trouble sorting through all the information her senses are taking in, she often seems confused -- aware and bright, perhaps, but confused. This child may respond to parts of a situation rather than to the whole situation itself. Some examples of the more specific perceptual problems a child with MBD may have are: discriminating differences in sizes of objects; discriminating spatial concepts; difficulty with body image; discriminating familiar objects by their feel; discriminating an object from the ground space around it; reversing the image of a letter or a word.

These are just a few examples. You may see a few of these traits or several. No two children with this disability are alike.

Perception can be thought of as the process that helps organize a person so he can think and learn. Here we have described a child who, although intelligent, may have a hard time putting together the things he has learned and understood so that he can use them to learn additional things and perform certain tasks.

A word of caution is crucial here. The characteristics described can be seen in most children at some time. It is only when they persist far beyond the age when these are appropriate and when they exist along with perceptual --learning difficulties -- making an intelligent child seem unusually out of step with other kids his age -- that we may suspect that he could have minimal brain damage.

******KEEP IN MIND -- disabilities and handicaps do vary in degree, do range from being very mild to very severe. Remain flexible, as staff and

parents, in both your outlook on and your approach to the whole child. Be thoughtful, cautious and precise in describing any child, and don't jump to easy labels or definitions just to solve a problem or get out of a difficult situation. Finally, terms could be useful as a "common language" AS LONG AS THESE TERMS AND LABELS ARE NOT THE ONLY WORDS USED TO TALK ABOUT CHILDREN WITH SPECIFIC DEVELOPMENTAL PROBLEMS.

Please remember, too, no child grows easily, evenly, or perfectly. The various handicaps and disabilities we have outlined are not to be matched up with whichever child at your center seems to be out of step, for the moment. It is a good idea to get help for any child whose behavior, whose total picture, seems to be out of step over a period of time or at an age when such behavior is no longer appropriate. This knowledge about handicaps is to be used not to label, isolate, or separate children, but to help children with problems grow and develop in spite of their specific difficulty. Please read our glossary, which follows here.

IV. GLOSSARY OF TERMS:

The words defined in this glossary are some of those often used in reports, discussions, articles and books concerning disabilities. These are only some of the words which we feel may be helpful for you

to understand. There will be other ways of looking at their meanings.

aphasia: loss of the powers to speak, write, or understand words; caused by brain injury or disease.

autism: characterized by severe difficulties in communication, behavior, and in relating to other people. These are often very attractive, healthy-looking children who appear disinterested in the world of people, yet they are fascinated by objects and by themselves. Some are resistant to change. They may show mannerisms such as walking on tip-toe, waving hands in the air, tapping with fingers on people and objects, or spinning objects. Children with autism may have severe problems with eating and/or sleeping, may show absent, delayed or irregular speech development and may have moments of unprovoked laughter or crying.

behavior problems: a pattern of behavior not appropriate to a specific given setting (home, school, grocery store, etc.). The behavior can go from extreme withdrawal to very, very active noisy behavior. How the child acts affects his ability to function. This child also may be called: "acting-up, hyperactive, hard to handle, difficult, disruptive child". Neurological damage can cause behavior problems.

birth defect: refers to an injury to the child during its pre-natal development or birth.

blind: loss of sight.

bow-legs: legs which curve away from body often making walking difficult.

brain-injured; brain-damaged: person who has had an accident, illness or birth injury which affects the brain's function.

cerebral palsy: a condition characterized by disorganized motor control and muscle coordination. The central nervous system has been damaged before, during or after birth. Often, intelligence is not impaired, yet communication may be affected. CP may be mild to severe.

cleft palate: roof of the mouth of a person is improperly developed, causing impaired speech and difficulty eating. There may be an opening in the upper lip which sometimes requires surgery.

deaf: loss of hearing.

developmental disabilities: any problems related to growing up, to developing; originating in childhood. Term is now used frequently by Agencies to refer to Cerebral Palsy, deafness, emotional disturbances, mental retardation, speech problems, and brain injury.

Downs Syndrome: refers to a child born with a genetic condition which was formerly called "mongolism." This genetic condition causes mental retardation and specific physical features such as loose joints, poor muscle tone, flattened nose bridge, slanted eyes, and short, frequently pudgy stature.

dwarf: specifically a birth defect which affects body growth resulting in abnormal proportions. Only some of the bones will be affected or the growth of different bones will be affected in different ways. In addition dwarfism is sometimes used to refer to all short sized people. Many people with this condition have banded together into an organization called "The Little People of America, Inc.".

EEG electroencephalogram: a diagnostic tool which measures electrical activity in the brain and records it in wavy lines on a moving strip of paper. These brain wave patterns can sometimes identify areas of difficulty in the way the brain's electrical system works. The test is completely painless.

exceptional child: is a child whose educational needs differ from those of the average child. Used to refer to all differences from the norm including the gifted.

hairlip: a birth defect in which there is an opening in the upper lip sometimes requiring surgery.

hearing impaired: damage to hearing ability.

hydrocephalus: a condition in which an unusual amount of fluid accumulates in or around the brain. Usually, the child's head is enlarged. The amount of fluid that accumulates can vary. Surgery is sometimes performed to insert a shunt to drain off excess fluid. Mental retardation need not always accompany hydrocephaly.

hyperkinetic; hyperactive: an extremely active child who cannot control his activity; his activity does not seem to have any purpose. Sometimes, this child's activity may cause a difficult management problem in the classroom. Watch out -- frequently the term "hyperactivity" is accompanied by a prescription of a tranquilizing drug. Be clear about why that drug has been prescribed; drugs can be helpful for some children, but ask questions to be sure the reasons are valid. This term should not be applied to a restless child who is just bored by school.

learning disabilities: a broad term applied to the many varieties of difficulties a person might have in certain areas of learning.

lip reading: a technique of comprehending someone else's speech by watching the movement of the lips of the person talking.

mongoloid child: see "Downs Syndrome."

nervous system: refers to the brain, the spinal column or cord, and the nerves of the body.

paralysis: the loss of feeling or movement in a part of the body.

paraplegia: paralysis of the legs or lower part of the body.

petit mal; grand mal: convulsions, seizures; are two types of epilepsy; usually controlled with medication.

phenylketonuria; PKU: a metabolic disturbance which, if not corrected through proper diet beginning right after birth, can cause mental retardation.

peripheral vision: awareness of what is to each side when eyes are focused straight ahead.

midget: a birth defect which affects growth of the entire skeleton to equal degree. A midget's body is formed evenly and proportioned normally although being unusually small. Growth, rather than intelligence is affected primarily.

sign language: a way of communicating using letters, words and phrases formed with one's hands and fingers. No verbal speech is required (but often accompanies it!) Hearing and speaking children and adults can be taught sign language to help communicate with deaf people and speech-impaired people.

slow learners: literally, children who are learning slower than the others of their age. The term is very vague and that doesn't explain what particular educational needs that child has.

special child: a child needing extra help (yet, don't all children need this?)

special education: instruction for and about children needing extra help, in some areas of learning.

special schools: schools for children who need more help than most children in order to grow to their fullest potential.

spina bifida: is a defect in the bone structure of the spinal column. There are three types. In the least severe, the person is able to function normally but may have a small hairy spot on the back. The second is more serious, and occurs when some of the internal material (nerve roots and fluid) from the spinal column slips out between the bones forming a cyst or lump that can be seen. After surgery, the person often can function normally. In the most extreme form, (myelomeningocele), a piece of the delicate spinal cord itself slips out into the lump or sac on the back. In this case, a person may lose feeling in the nerves in the lower part of his body.

spinal curvature: physical malformation in the spinal column, making the back crooked.

stereotypic movements or mannerisms: can be repeated swaying, stroking, tapping, rocking, spinning or head-banging motions. These are often observed in children who are thought to be autistic (may be called 'autistic-like behaviors') but may be seen in children who have mental retardation or brain injury. Some people working with these children feel that the repeated movements are used to close out the outside world by providing the children with an internal world of self-stimulation.

syndrome: a set of symptoms.

total communication: training in communication for a deaf person using sign language, lip-reading, gestures, speech and hearing aides.

tremor: an involuntary shaking or trembling of muscles.

visually impaired: some damage to the ability to see.

V. SLANG WORDS - PLEASE LEARN NOT TO USE THESE

These words are inaccurate and often hurt the feelings of a handicapped child and his family. Please use a more accurate description of a child's disability, instead.

acts up: inaccurate description of a very active child who may have a real problem and needs help.

backwards: handicapped

cripple: physically disabled.

deaf and dumb: usually "mental defective" -- retarded.

dummy: retarded; deaf; unable to speak; imbecile; moron; idiot; dull.

fat slob; fatso: overweight.

feeble-minded: retarded; mentally ill, etc.

four eyes: someone using glasses.

has the fits: gets convulsions; seizures; has epilepsy.

freak: anyone who is different.

hunchback; hunch: curved back.

hyper: from hyperactive

idiot: originally, person with mental retardation

limpy, gimpy: physically disabled.

mental: has psychological or behavior problems.

mongolian idiot: person with Down's Syndrome, unfortunately still used today by doctors.

moon-face: person with Downs' Syndrome

psycho: mentally ill or disturbed

retard: retarded; slow

schiz: short for schizophrenic

spaz: child lacking muscle control; is awkward when he moves.

the foot: someone with deformed foot or who uses a crutch

this child is "not right": handicapped

water on the brain: hydrocephalus

Please turn the page to read the Bibliography, part VI of this Section.

VI. BIBLIOGRAPHY - To help you learn about handicapping conditions, about children who have them, and about their families.

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Section 2

THE CURRENT PICTURE IS NOT PLEASANT

I. General Prejudices Against Disabled People and the Deaf Child Specifically, by Marge Feig 2.1

II. The "Cast of Characters" in New York City -- Their Positions as we See Them Now Involved with Handicapped Children. Day Care and Head Start Discussed 2.4

III. What Choices Exist for Families Who Want to Educate Their Handicapped Child? 2.9

Part I was prepared by Marge Feig, a staff member of the Day Care Consultation Service. She is concerned with the problems which deaf people encounter in their everyday existence and would like to see them accepted by people and new avenues of communication opened up to integrate them into society.

THE CURRENT PICTURE IS NOT PLEASANT

I. General Prejudices Against Disabled People and the Deaf Child Specifically, for Example.

Education has supported prejudices against handicapped people. Unfortunately, schools in the New York City area have perpetuated feelings of hate, fear and distrust toward individuals with handicaps. Handicapped children are clumped together in segregated classes away from children without handicaps. School personnel and parent associations within the public education system have not, as yet, made a powerful enough effort to educate others about, or to welcome into their mainstream, children with handicaps.

Public and Private Institutions have supported prejudices against handicapped people. Except in rare instances, you do not see physically handicapped people at work, earning wages, in our society. They are just not hired -- they are considered inferior in both mental and physical capacity.

Architects and construction builders do not design buildings with elevators, toilets or doorways large enough to take a wheel-chair. Railings along walls are not provided to aid the mobility of a person with a handicap. City engineers do not make low curbstones or construct ramps next to stairs which could help a person with a crutch or wheel-chair.

Getting on or off a bus can be difficult for all of us. Imagine the process for most handicapped people!

Too little is being done now to broaden our awareness and acceptance of individuals with disabilities. Unless confronted with a handicapped person, most people tend to close their eyes, or look away from, an unhappy human condition. Because people look away, they don't think about the causes of an affliction, nor do they see the results of that affliction, and how it has affected the person who is handicapped. People who themselves are not handicapped are affected, particularly if they have a handicapped child in their family, particularly if they see the same handicapped person every day in their neighborhood and are able to do nothing. When people turn away, whether they realize it or not, they support overwhelming fears so prevalent in our society toward handicapped people. For many of us, it is easier to do nothing and to believe that others are taking care of all those handicapped persons. It is not true -- each needs to be responsible.

The segregated and "oral emphasis" on education of deaf children continues the isolation of handicapped people. Most deaf children go to special schools to get their education and training. Most often, the schools for deaf children use only one approach towards dealing with the child's hearing loss. Rather than teach a child how to communicate totally with lip-reading, speech and hearing aides, and sign language so that the child could be well-equipped to move into an integrated setting, most schools still support the "oral theory" of education of deaf children.

The "oral" approach does not permit sign-language to be used. This approach believes that only after a training program in lip-reading and in using hearing aids to magnify whatever small mount of hearing is still present will the child be able to communicate with others. Yet, often for those of us not used to a deaf person's speech, it is still difficult to understand and respond, because we have had no contact and no training. This seems to be a one-sided education.

Too little is being done to broaden the choices a deaf person (or a hearing person) has in attaining the right to communicate with all people whether they are deaf or not. The use of total communication: sign-language, speech and lip-reading, certainly would reduce the isolation a deaf person feels. Acceptance by non-deaf people would be heightened. Those of us with hearing could learn sign language in the same way one learns a foreign language. The total responsibility for learning to communicate becomes a double-task -- not only relegated to a hearing-impaired person but also becomes part of the education and responsibility of a hearing person. There really is a necessity to somehow integrate with each other those people who receive both highly specialized education and what is considered to be a more typical education. It is now time to break down some of the existing barriers.

Pre-School Programs

Pre-school programs usually think of including handicapped children as a big "extra" -- requiring extra funds, training, and back-up services. This kind of thinking is enough, in most cases, to prevent accepting handicapped children into any pre-school program.

We should be worrying about how it is that we've excluded a group of children for so long.

There is no "perfect time" to start an integrated program. Begin now -- perhaps set a date to work toward including some handicapped kids in your program. You will prevent some handicapped children from sitting at home, probably bored and lonely; and you will permit a parent to have some independence. You will help change some very long-standing prejudices and fears that have prevailed in our system of educating young children. Become a part of this change -- help bring it about!

Hard to believe -- in New York City there are families and children who need classes now, January 1975, and there are pre-school programs with empty spaces waiting to be occupied by children with handicaps. What is going on here?? WHY? Can't they get together?

The Parents of Handicapped Pre-School Age Children

Unless a parent sends his or her handicapped child to a residential institution, most parents have their handicapped child live at home with them. Like any other parent, parents of handicapped children want their child to play with other children, to go to school, to develop as fully and completely as is possible. Parents have a special urgency in their efforts to find or to create a program that will not totally isolate their child from contact with the "normal" world. Yet, this urgency often makes them place their child in any program available, regardless of quality.

Parents need help to become more selective and more confident about what they want for their child. They need to learn how to speak up for services they are not getting. They need to feel a part of their community by assuring their child his rightful educational place.

The Parents of "Normal" Children

Many parents of "normal" children do not want their children to attend school with handicapped children. They are afraid their children will learn bad behavior or language habits from a child who is handicapped. Often parents are afraid their children will "catch the handicap." They fear their children will be slowed down, bothered and distracted by a handicapped child. And these parents may even by jealous of whatever extra or individual attention a handicapped child receives. There are many basic fears, and they must be recognized and dealt with by having workshops, educational films, or whatever is necessary to raise your parents' awareness and understanding about handicapping conditions. It is crucial to help parents in this way. Once they get over their own fears, they can help their own children understand, accept, and be unafraid of "those" children. Hopefully, then parents, children and staff will soon see positive reasons for integrating their program.

Children and Adults

Most adults' fear of anyone different affects the way their children treat other children. When a "normal" child teases a handicapped child, for example, that handicapped child and his family become fearful and distrustful of exposure to the "real world." Often the teasing comes from fear and prejudice rather than from a more natural disagreement that arises between friends or rivals. We would hope that having young children together in an integrated setting could put them on more equal footing and put an eventual end to a child ridiculing another because of her handicap. Right now, this just is not happening because adults are not expanding the horizons of education for all young children. And now, in January 1975, the step forward to more integration is still very, very slow.

The Specialized Agencies for Handicapped People

Traditionally, many of these Agencies serving people with specific handicaps begin their services for children at age five. When they do have a pre-school program, it is often part-time, small and segregated into a setting just for children with handicaps. The agencies need to open more early childhood programs, and to reach all children.

Happily, in 1975 as we re-do this, some of these specialized agencies are beginning to broaden their approach and are stepping out into their communities. Help them keep this up.

The Government Agencies

The City, State and Federal Agencies traditionally are long on talk and short on action. They have the power to control services for handicapped people; they have the power to negotiate for adequate dollars to provide the much-needed services. Yet they have not, traditionally, been able to produce the money, the services, or even the training to set up much-needed programs for young handicapped children. Government Agencies are usually not sympathetic to community people or parent groups wanting the funds to begin their own programs; they prefer "professionals."

There are funds for programs for handicapped children of day care age. (How to get them is the problem. See "Funding," Section V.) Now there are a few programs started by community and/or parent groups funded by government agencies in the NYC area. These programs operated on their own, often for years, before an agency considered them competent, or "professional" enough, to warrant their financial support. And, sad to say, it takes an awfully long time to get a program ready for government funding.

Many new programs are needed to help those children who have handicaps. Can you do it? Pre-school handicapped children can come into day care and nursery settings without extra government funds, and their usual restrictions.

Laws

Here are two New York State laws specifically for handicapped children and their families: One is law #4407, familiarly known as "the Greenberg Law," and is for handicapped children age 5 and over. This law provides money to pay for busing; and to pay $2,000 towards the tuition of handicapped children in special schools when the child cannot attend public school. Often "State reimbursement plan," or "tuition reimbursement" is used to refer to the #4407 law.

The second is Family Court Act #232. Under this Act, money is awarded by the Courts to a family who needs tuition for their child to attend a "special school" -- other than the public school. The decision that the family needs this tuition and that the child needs the "special" schooling is made in Family Court. There is no minimum age requirement nor any "financial eligibility" test to pass.

Right now, many exciting possibilities are opening in this whole area about handicapped children and what the laws can get them. Please call for specific information and help in using these laws:

Community Action for Legal Services, Inc.
335 Broadway
New York, New York
966-6600

Legal Aid Society
Law Guardian Family Courts
235 West 23rd Street
New York, New York
243-1392

MFY Legal Services, Inc.
214 East 2nd Street
New York, New York 10009
777-5250

New events. The New York State Education Commission ordered the Board of Education to place all students with diagnosed handicaps in appropriate public or private school classes. This order has been called "The Nyquist Decision." Since February 1, 1974, all handicapped children have been placed in classes, theoretically. If your child is 5 years old, or older, and has a diagnosed handicap and is not in a public school classroom, find out why. Call one of the legal services we have listed here.

Day Care and Head Start

Day Care --- in New York City. There are over 400 City-funded day care centers in New York City. Each center is run by a Board of Directors, and also is supervised by the N.Y.C. Agency for Child Development, (A.C.D.).

Until late 1973, there had been no "official" A.C.D. policy where handicapped children were concerned. As sometimes happens, some of the children a center admitted did have handicaps which were discovered as the day care center's staff became familiar with its children. In December 1973, the Agency for Child Development had outlined its "Official Policy: Mental Health Concept," which described how handicapped children would be managed in Day Care. A.C.D. would offer day care services to a small number of handicapped children -- only 100 places in total were available for 1973-74 in N.Y.C. (Needless to say, this was too few handicapped children getting into the centers! But, it was a start towards officially admitting that handicapped children have a right to attend the centers with other children.)

A.C.D. and the City Bureau of Mental Health and Mental Retardation cooperated to fund projects to have a few handicapped children attend a few centers. "Backup services" were provided: consultants, therapists, clinical diagnosis and referrals from hospitals and clinics receiving Federal grants to do this work with day care children. A.C.D.made a similar arrangement with United Cerebral Palsy, New York City.

A.C.D. then put out guidelines about how, specifically, a program for handicapped kids would have to function to get funds. This involved questions about who has power and control to admit or reject children, which people you hire to be your Staff, which qualifications you must have if you are to be "head" teacher, and what hours your program must be open and operating. Often these guidelines were confusing and caused a great deal of inner strife and conflict throughout centers. Often it was enough to keep centers from having any handicapped children.

Right now, in January 1975, there is more awareness in day care centers as to their responsibility towards handicapped children and their families. Staff and parents are deciding how they can get together to provide appropriate education for all their children. We support their vision.

Head Start Today in New York City. Last year, 1973-74, new Federal guidelines mandated that Head Start centers include handicapped children as 10% of its regular program. This means that for a 60-child Head Start center 6 of the children should have handicaps. Not surprisingly a very token sum of an additional $100 per child per year has been allotted to provide handicapped children with a program. This $100 is not to be used to hire new staff but is to be used to get special training for the regular Head Start staff and to purchase equipment. It remains to be seen what each Head Start center will do, but we hope that a Head Start center would make the effort to get out into their community and find handicapped children, maybe a sister or brother of a child in the center already. Be creative -- don't let the project fail until you have tried all possible ways, some discussed in this handbook, of including handicapped children into your Head Start program.

In January 1975 there are Head Start centers providing space for training workshops to learn about handicapped children. Some Head Start centers are really trying to meet their mandate both sensitively and appropriately. It has not been easy. We hope they will keep at it and not stop their efforts!

III. Current Choices for a Family Who Wants to Educate their Handicapped Child

1) A family can try to enroll a child in a special program for handicapped children. Often because day care groups and pre-school programs assume there are lots of programs for handicapped children, they do not reach out to include handicapped children in their centers. But, there are only a small number of pre-school programs available to handicapped children and their families. There are long waiting lists; the programs that are available are most often part-time and are usually far from a child's home -- requiring a long bus ride. A lot of programs focus on "parent-counselling" (meeting twice a month, for example,

with a social worker) which can be helpful but does not meet the child's immediate need for schooling. These specialized programs traditionally exclude "normal" children because some parents of handicapped children do not want their children in integrated settings. They feel their child will not get the kind of attention necessary. They may be feeling a hostile attitude from others. They may feel frightened of how "other" parents would respond to them and to their children -- either too much sympathy, too much pity, or real fear of the handicapped person in general.

2) Families can try to get their handicapped child into a private regular pre-school; but because they expect to be rejected, most parents of handicapped kids do not even approach a regular pre-school program. Private nursery schools often charge expensive tuition. These schools probably would not give a scholarship to a child with a handicap. (Read our "Resource" Section to learn which schools do take a few handicapped children.)

Perhaps, #232 Act could get private nurseries to take handicapped children; this should be pursued by families.

3) Families can try to get their handicapped child into a publicly-funded day care center or Head Start program. Not many of these programs in operation now are open to handicapped children. (Read our "Resource" Section, Section 4, to learn which centers have funded programs; we need more.)

4) A family can keep its young handicapped child at home. Use some of your own resources to get some services in your home for your child. Perhaps the following suggestions will help:

a relative or friend to babysit,

a home-training service from a hospital or clinic,

the Developmental Service located in your borough,

reading books and pamphlets about what other families have done,

check our "Resource" Section in this handbook.

5) A family can join with others to start their own unfunded program. We believe this is a very important consideration. It can be fun, is rewarding (and probably won't be the easiest thing to do!). It is the most direct way to get some help going for your own kids and those in your neighborhood with similar needs. This kind of program helps parents share their questions, problems, and experiences. Together, they can tackle prejudices against handicapped people by planning from their beginning for an integrated program. It is also your most direct way to control present and future development of your own children.

We support parent-initiated and parent-operated programs because they can deliver the supportive, responsive, self-reliant and flexible programs we all need. And, these goals can be accomplished on a small basis with four children meeting together in one of the homes, for example:

In the following sections of this Handbook, we give some ideas on beginning to think about planning and operating a program for young handicapped children.

Section 3

INTEGRATING HANDICAPPED CHILDREN IN YOUR CENTER

I. Who Might Decide To Do This? 3.1

II. How Do Your Staff and Parents Feel About Handicapped People? Talking About Fears and Prejudices 3.1

III. How Many Handicapped Children Will Attend Your Center? . 3.2

IV. Integration v. Separation: A Conflict For Some; Our Point of View to Consider 3.3

V. Getting Handicapped Children To Come To Your Center . . 3.5

VI. Back-Up Medical Services for the Handicapped Children In Your Center 3.6

VII. Staff and Staff-Training 3.6

VIII. Inform and Involve All Parents and Staff 3.8

IX. Setting up the Program -- Similarities To Your Present Program 3.9

INTEGRATING HANDICAPPED CHILDREN INTO YOUR CENTER

I. Who might decide to do this?

-- Parents of children already attending your center.

-- Staff of your center.

-- The Board of Directors of your center.

-- The Agency for Child Development.

-- Community people.

-- Parents of handicapped children living near your center.

-- A private agency from your area which needs a space to run its program.

II. How do your staff and parents feel about handicapped people?

Talking about fears and prejudices --

-- ask staff and parents what their personal experiences with handicapped people have been;

-- find out how each feels towards and reacts against a handicapped person: fear, hate, disgust, pity, excessive kindness, belief that handicapped people can't do anything;

-- plan some workshops about handicaps and their causes. Learn the facts;

-- invite parents of handicapped children to talk with your staff and parents. Let them tell their experiences with their own children;

-- show films, videotapes;

-- visit other centers or special programs with handicapped children to talk with their staff. Invite teachers to talk at your center about their experiences;

-- you might get a nurse or doctor who likes handicapped children to talk about their physical care;

-- read pamphlets, books, and articles about specific handicaps and about children who have them. Parents have written and published books about their own children

which are very encouraging and moving. (A brief list of such books is in the first Section of this Handbook.);

-- talk about handicapped children and their relationship to your center. Will other children be with them, play with them, tease them? How will parents of the other children in your center feel when you have children who have crutches, wear hearing aides, or have unusual physical features? Be sure to talk about the positive reasons for integrating the program: children learn to help each other, and learn not to fear handicapped people;

-- be flexible in your pre-planning and during your early stages of thinking and talking. Remember: there are various ways of developing a program to integrate handicapped children into your center. Decide what is best for you.

III. How many handicapped children will attend your center?

-- Take only the number of children your staff and parents feel comfortable about accepting.

-- Take only the number of children you have space for:

- If your center is already enrolled to the maximum number it might be able to add one or two handicapped children per classroom.

- If some children have moved away from your center, it could be possible to fill their places with handicapped children from your neighborhood.

- If your center has a centrally located unused room -- one that is not isolated away from the main action in the center -- you could arrange it as the home base for your handicapped children. They could spend part of each day there participating in programs planned especially for them. During the rest of the day some of the children could go to other classrooms in the center to be with unhandicapped children, and vice-versa. Be careful that this home base does not become the "dumping ground for problem kids!"

IV. Integration vs. Separation: a conflict for some; our point of view to consider:

-- Some centers may not want to integrate handicapped children and unhandicapped children in the same classrooms.

-- These centers will choose a more conservative approach: a traditional method of having only handicapped children together with their own teachers in a separate classroom because they feel at ease with this.

-- We feel separation is unhealthy for the following reasons:

- It isolates handicapped children and unhandicapped children from contacting one another;

- it copies the approach of the public schools which place handicapped children in a "different" program;

- it does nothing to challenge the way classes for handicapped children have operated;

- it makes teachers and other professionals feel good about how much they are "helping the 'poor' handicapped child" when they only see a child in a setting with others who are the same; the child is never allowed the healthy, if often painful, experience of working to gain acceptance from non-handicapped children and their teachers;

- it supports parents' attempts to find a schooling situation that is the least painful for them. This usually means they find a situation they regard as protective of rather than challenging for their children and themselves. (I can hardly blame them for this -- we are conditioned from the birth of our handicapped children to believe that only the professional, specialized setting is best for our kids to be in,);

- finally, it continues to support rather than change or improve the way things have always been for handicapped people in our society.

-- We believe integration in your center is healthy for these following reasons:

- It helps children without handicaps learn some facts about handicapped children; ask the children in your center what they think;

- it helps children without handicaps learn how to be in the same room with handicapped children and not point them out as "odd": this may take time and that is O.K.;

- your center can serve more children and meet your community's needs in a better and more representative way;

- children and adults develop an appreciation for rather than fear of others with handicaps;

- it confronts adults with their own fears;

- beginning in the early childhood years is a good time to develop tolerance in young children;

- it sets up an opportunity for peer group relationships where children learn socially and intelletually from one another;

- your children can learn sign language to expand their abilities to communicate;

- your children learn that one can be alive, and function, with a handicap: a person doesn't have to be "perfect" in order to live;

- it helps prepare children for a time when they could have an illness or an accident which would leave them disabled: they will be more ready to manage themselves because of their early familiarity with others who manage, too;

- please add your own thoughts, feelings, and experiences here.

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-- We understand and recognize that there are handicapped children who cannot go into an integrated day care or pre-school setting. We believe it should be up to your center to decide which handicapped children it cannot help.

V. Getting handicapped children to come to your center:

-- The family worker in your center may know which sisters and brothers of children already in your center may have handicaps.

-- Find out through friends in your neighborhood which families might have a young handicapped child. Then try to interest these families in what you are doing.

-- Contact churches and synagogues in your area to tell them about your program.

-- Have only neighborhood handicapped children attend your program. It is much easier for a parent to carry or wheel his/her child down the street than to take the child on a long subway or bus ride.

-- Spread the word that you need handicapped children through:

- agencies serving handicapped people (see "Resource" Section in this handbook);
- newspapers, newsletters, Community bulletins;
- radio stations, public service announcements, talk shows;
- local public and private pre-school programs;
- health stations, clinics, hospitals, doctors, nurses;
- the "Developmental Service" in your borough (See "Resource" Section in this handbook);
- putting up posters in stores in your neighborhood;
- telling us at the Day Care Consultation Service, 663-7200, extension 225.

-- Keep in mind: If the Agency for Child Development and the Bureau of Mental Health and Mental Retardation are in cooperation together to fund your program, you might not have the control over selecting your handicapped children. Because these two agencies are working with hospitals to provide diagnosis and referrals of children with handicaps who are eligible for day care, ACD could try to decide which children come to your center. In this case, handicapped children could come by school bus to your center from outside your neighborhood, and handicapped children from your neighborhood might not be able to attend your center. Remember, you have a right to say what you want. In other words, it should not be requisite that you need give up anything just to have a handicapped child come to your center! Ideally, your center should be able to decide which child attends and should be promised that the child you choose gets the necessary "back-up" services from the powers that are in charge. (Section 2 in this Handbook discusses what agencies do. Please refer to it or call us at 663-7200, extension 225.)

VI. Back-up medical services for the handicapped children in your center:

-- Call the "Developmental Services", in your borough to see what they will do for your center;

-- call local Health Stations, Hospitals, Clinics to see what they provide;

-- ask parents what services they have already;

-- ask other day care centers what services they get, and how;

-- ask a family's doctor; your own doctor;

-- call City agencies for information;

-- call private agencies serving only handicapped people;

-- organize a Health Team in your center to see that all children in your center get the medical services they need.

VII. Staff and Staff Training

For many centers, getting staff who can work with handicapped children becomes a major consideration and even a problem. Often,

a center in its understandable eagerness to succeed feels they must hire only highly trained "special education" people to work with their handicapped children. Possibly, the center is afraid an unqualified person could damage the kids.

We feel that it is possible to have people work with handicapped children who have not had any special training when your program begins, as long as these people are willing to seek and accept some kind of in-service or on-the-job training from others who have had experience, and as long as the people really like children and can accept those with handicaps as people. Remember that you will be working with children; and handicapped children are children! They have needs -- it will take sensitive adults to see that these needs are met.

-- Who can your staff be? Here are some of our suggestions:

- a parent of a handicapped child;
- a friend from the community who has had some familiarity with handicapped children;
- a friend who likes children and wants to learn how to teach handicapped children;
- a student teacher;
- a relative;
- someone on your present staff who wants to work with handicapped children;
- any combination of the above;
- your own ideas.

-- Staff training can come from your own resources. If possible, the parents of the child can be part of this resource. For example, one center arranged on its own to have a nearby college spe-

cial education program do in-service training at its center. Get all your staff involved in talking about how the training should progress. Plan workshops; have people come to your center who have worked with handicapped children. Be clear about your program's goals. This clearness should help you decide what action you need to take first that will give your staff some techniques and skills in beginning their work with the handicapped children attending your center.

-- Recognize that at the beginning you will not know all the answers to each situation that arises.

-- Remain flexible in your thinking and planning so that you can adapt your program to the needs of each specific child. Remember, there is no one way of doing a program for any children!

VIII. Keep all the parents and all the staff in your center informed and involved in working with and planning for a handicapped children's program:

-- The best way to build up everyone's resentment towards "all those handicapped children" is to be exclusive or secretive in planning!

-- Constantly ask for ideas and suggestions.

-- Hold workshops and repeat the whole thing about expressing fears and prejudice. Don't put people down for feeling uneasy. Help them understand why they do, if possible.

-- Always keep your program's goals in mind. Be as realistic as possible about what your center as a whole group will be doing.

-- Bring together the parents of children now in your center with those parents whose handicapped children will start in your center. Each can learn from the other's personal experiences with their own children. Let the parents of the handicapped children talk about the fears they have for their children. Break down barriers whenever possible!

IX. From now on, setting up your program will be similar to what you did with other classes in your center:

-- Rely on your past experience with young children;

-- check out and talk with staff at some of the centers we list in our Resource Section to find out what they did, if you think you need help or have specific questions about equipment, space, etc. Make use of their experiences;

-- you can do it!

X. Please tell us what you are doing, have done, so that we can continue to learn. Phone (212) 663-7200, extension 225.

Section 4

RESOURCES IN THE NYC AREA FOR DAY CARE GROUPS WHO WANT TO KNOW ABOUT HAVING HANDICAPPED CHILDREN IN THEIR CENTERS.

I. Programs to Visit 4.1

II. Specialized Agencies 4.4

III. City Agencies 4.7

IV. Additional Resources 4.10

RESOURCES IN THE NYC AREA FOR DAY CARE GROUPS WHO WANT TO KNOW ABOUT HAVING HANDICAPPED CHILDREN IN THEIR CENTERS.

I. Here is a list of day care centers with programs which both integrate "normal" and handicapped children together, as well as having them in their own separate classes. We visited these centers, have talked with teachers and directors. These centers welcome visitors -- but please call first!

The programs we note here resulted from these centers' knowing what they wanted to do, DOING IT, and then reaching out for public funds to expand their efforts. You can do it, too!

In the Bronx
Children's Circle Day Care Center
1332 Fulton Avenue
Bronx, New York
Director: Ms. Barbara McCrae
378-1330

This center was begun by local community groups. It has some handicapped children in each classroom, with an extra teacher in each room to help when necessary. Additional special help comes to the center from consultants. This center is city-funded and has a federally-funded outreach project to train others.

These Our Treasures
3471 Fenton Avenue
Bronx, New York
Director: Ms. Teddy DeSoyza
882-2280

This group of parents began their own program from scratch, using friends as volunteers and consultants when needed. They know a lot about beginning and running their own unfunded center for infants and young children with handicaps. They have recently gotten funding through the Department of Mental Health & Mental Retardation.

In Manhattan

Champ-Morningside Children's Center
311 West 120th Street
New York, New York
Director: Ms. Roz Williams
864-0400

A city-funded Montessori-oriented day care center, Champ had taken in some handicapped children on its own. As this booklet 1st went to print, Champ had just received money for its planned program of integrating handicapped children into their regular Montessori classrooms. Their plan for integrating is very well thought out and you should call Ms. Williams or Ms. Cook to talk. Their program sounds like a good model for others.

Riverside Church All-Day Program
Riverside Drive & 122nd Street
New York, New York 10027
Director: Ms. Josephine Bliss
749-7000

This city-funded program has a few handicapped children in each class. There are both retarded and physically handicapped children here. Ms. Bliss knows a lot about the attitudes and prejudices a group wanting to integrate will face. Her advice will be helpful.

In Brooklyn

Low Memorial Child Care Center
50 Monroe Place
Brooklyn Heights, New York
Director: Ms. Clara Exum
Head of Special Class: Ms. Dorothy Broms
237-0958

This city-funded center has a program for very handicapped children. These children attend a separate class until they are ready to go into other classes in the center. Even then, these handicapped children may spend only part of the day in a regular class. The Director has experience talking with parents, staff, and has worked with many different children. It is worth visiting the center, to talk with Ms. Broms and to see how the staff works with the children both individually, as well as preparing them to be together in a group.

Spring Creek Early Childhood Center
888 Fountain Avenue
Brooklyn, New York 11208
Director: Ms. Pat Greenwald
257-8900, extension 308

Visiting this center will help you plan your program, order your equipment, organize your staff, and think about involving parents in your program. This well-equipped and staffed center has planned carefully to work individually with each child of varied handicaps. **Be sure to talk with the staff.**

We visited these two Nursery Schools with handicapped children in both separate classrooms and in regular classrooms. These nursery schools are private, tuition-charging schools, although their programs for handicapped children do receive extra funds. Call to visit.

Riverside Church Nursery-Kindergarten
Weekly School
Riverside Drive & 122nd Street
New York, New York 10027
Director: Ms. Josephine Bliss
749-7000

This school integrates some mentally retarded and physically handicapped children in its classrooms. Because the programs for every child are quite individualized, the staff has time to spend with all the children. The school is well-equipped and staffed. The director is in favor of integrating, talks openly about her experiences. There are classes for only handicapped children, too.

Brooklyn Heights Montessori School
124 Montague Street
Brooklyn, New York
Director: Mr. Daniel Pociernicki
855-2775

This school has its children both separated and integrated. The ratio of staff to children in the separate program is nearly one-to-one. The program for each child is individualized. (The staff was open and talkative when I visited, and met after each class with me to talk about their work.) In the regular classrooms there were one or two handicapped children who had been in the separate program previously.

If your day care staff wants to see specialized programs for only handicapped children, we suggest a few to visit. Your staff will have a chance to talk with and to see teachers and therapists who work only with handicapped children. Call the program directors to arrange to visit. And for more information about programs, please call the Specialized Agencies listed on page 4.6.

Deaf Children
Lexington School for the Deaf
26-26 75th Street (75th & 30th Avenue)
Jackson Heights, New York 11370
Dr. Oscar P. Cohen
899-8800
(Nursery level is integrated: hearing and deaf)

New York League for the Hard of Hearing
71 West 23rd Street
New York, New York 10010
924-3230
(Ask for Community Outreach Program to get their Mobile Unit to your day care center)

Blind Children
We have not yet visited any programs for children with impaired vision. Please call the American Foundation for the Blind, 924-0420, for help.

Emotionally Disturbed Children
Riverside Church Therapeutic Nursery Classes
Riverside Drive & 122nd Street
New York, New York 10027
Director: Ms. Josephine Bliss
749-7000, extension 158
(This school class is affiliated with St. Luke's Hospital)

Alternate Solutions for Exceptional Children (A.S.F.E.C.)
4-05 Astoria Boulevard
Long Island City, New York 11102
Director: Bill Jesinkey
278-6700
(This group uses #232 Family Court Act to get money to its programs -- Read Section II of this handbook).

Children with Multiple Handicaps
New York University Center for Rehabilitative Medicine
400 East 34th Street
New York, New York 10016
Director: Dr. Ronnie Gordon
679-3200
(Mostly physical handicaps here.)

The Early Childhood Center
1731 Seminole Avenue
Bronx, New York 10461
430-3191 or 430-2200
Director: Dr. Nanette Doernberg
(Affiliated with the Children's Evaluation & Rehabilitation Clinic of the Rose F. Kennedy Center, Department of Pediatrics, Albert Einstein College of Medicine.)

Recreational Program for Handicapped Children
Manhattan Services for the Handicapped (All Handicaps)
342 East 54th Street
New York, New York; and
Mt. Morris Park Recreation Center
122 Mt. Morris Park
New York, New York
Directors: Karen Kushner, Fred Levine, Haressah Dawud
PL 8-3147
(This program trains its staff on the job. They will talk with day care people about their experiences. Call them.)

Intellectually Handicapped Children

Because we believe that most intellectually handicapped children could benefit in an integrated setting, we have not visited any schools for only retarded children. If you want to see one and talk to staff, please call one of the Specialized Agencies we list next on page 6 to find out a school near you to visit.

II. The Specialized Agencies are organizations for each specific handicap. The agencies have information about programs, meetings, legislation, literature, parents' groups, workshops, and camps which they sponsor. Call them for information; some have $5.00 membership fees per year, but joining is not required in order to get information. Here are a few; the telephone book lists more if you look up the name of the specific handicapping condition.

Association for the Help of Retarded Children (A.H.R.C.)
200 Park Avenue South
New York, New York
254-8203

Association for Children with Retarded Mental Development (A.C.R.M.D.)
902 Broadway
New York, New York
677-5800

American Foundation for the Blind
15 West 16th Street
New York, New York
924-0420

Alternate Solutions for Exceptional Children (A.S.F.E.C.)
4-05 Astoria Boulevard
Long Island City, New York
278-6700

New York League for the Hard of Hearing
71 West 23rd Street
New York, New York
924-3230

New York Association for Brain Injured Children/Association for Children with Learning Disabilities (N.Y.A.B.I.C./A.C.L.D.)
95 Madison Avenue
New York, New York
725-2280

United Cerebral Palsy of New York City (U.C.P.)
122 East 23rd Street
New York, New York
677-7400

III. In New York City these City Agencies are set up to give out information about services for handicapped people. These City Agencies do not provide the services themselves. These bureaucracies administer funds to programs for young handicapped children in the New York City area. They are the ones to pressure if you want more and better services for the handicapped children you know, or if you want to establish your own program with government funds. (See "Funding," Section V of this Handbook.)

Bureau of Mental Health & Mental Retardation
93 Worth Street
New York, New York 10003
566-2669

Bureau for Handicapped Children (for Physical Handicaps)
350 Broadway
New York, New York 10007
566-6000

Agency for Child Development
240 Church Street
New York, New York 10003
553-6461, 62, 63

(administers both Day Care and Head Start -- cooperates with the Bureau of Mental Health and Mental Retardation and United Cerebral Palsy, Inc., to plan funding for programs for children with special needs.)

In New York City, the New York State Department of Mental Hygiene has an office at Two World Trade Center, New York, and the phone number is 488-5872. Part of the State Department's interests are the State Schools and Institutions. Because of the focus on taking people out of the State Schools and returning them to their communities brought on by the Willowbrook Scandal, the State Department has formed "Developmental

Services" in the Boroughs of New York City. These Developmental Services are to focus on developing community services for handicapped people. Call the Services for specific information about programs for young children in your area; tell them what your center is doing now for handicapped children; also tell them what you need -- maybe they can help.

Brooklyn Developmental Services (two locations here)
888 Fountain Avenue, and 490 Fulton Street
Brooklyn, New York
625-6266, ask for Community Services

Bronx Developmental Services
1500 Waters Place
Bronx, New York
931-0600, ask for Community Services, extension 2046, 2047

Manhattan Developmental Services
75 Morton Street
New York, New York
924-2912, ask for Community Services

Queens Developmental Services
37-10 114th Street
Corona, Queens, New York 11368
672-9910, extension 200 or 226, ask for Community Services

Willowbrook Developmental Services
27-60 Victory Boulevard
Staten Island, New York 10314
698-1440, extension 131, ask for Community Services

In New York City, the Board of Education, 110 Livingston Street, Brooklyn, New York 11201 is in charge of City-wide school programs for handicapped children who are a minimum of five years old. It has a special office to administer these classes: The Office of Special Education and Pupil Personnel Services, 596-8928. Within this, there

are the following Bureaus which take care of specific handicaps:

Bureau of Child Guidance
594-4720

Bureau for Children with Retarded Mental Development
596-3085

Bureau for the Education of the Physically Handicapped
596-5199

Bureau for the Education of the Visually Handicapped
596-5087, 8

Bureau for Hearing Handicapped Children
596-5698

Bureau for Speech Improvement
596-5698

In New York City, the Department of Social Services is at 80 Lafayette Street, New York, New York 10003. The Special Services for Children is involved with handicapped children. Their phone number is 433-7479, and tell them what your center can offer young handicapped children.

IV. Additional Resources

"Serving Children with Special Needs"
Cost: $.75 - Stock #1701-0176
Order from: Government Printing Office
Washington, D.C. 20402

This is a booklet about planning, setting up, and operating day care programs for handicapped children. It has good sections on planning different programs for different handicaps and excellent bibliography of books and pamphlets to look for. You need this!

"How to Organize an Effective Parent Group and Move Bureaucracies"
Cost: $1.50 per copy
Order from: The Coordinating Council for Handicapped Children
407 South Dearborn
Chicago, Illinois 60605
(312) 684-5983

This pamphlet is excellent for both staff who want to know how to involve parents, and for parents wanting to involve others in their plans for handicapped children's programs.

The "Exceptional Parent Magazine"
264 Beacon Street
Boston, Massachusetts 02116
Published: 6 times per year
$10 - annual subscription

This magazine is published bi-monthly. Its articles are about children with handicaps. Staff and parents should read its articles about other parents' feelings and fears, their experiences, and what they do with their children. If your center does not want to subscribe, you may read a copy in the Bank Street Day Care Consultation Service, 610 West 112th St., New York City, or find it in your local library.

"Manual on Organization, Financing, and Administration of Day Care Centers in New York City"
Free to Community Groups; $5.50 for all others.
Order from: Bank Street College of Education Bookstore
610 West 112th Street
New York, New York 10025

This book is for community groups, their lawyers and other advisors. Part Seven refers to the planning of a Health Program in your center, and this could be particularly useful.

"Children with Special Problems: A Manual for Day Care Centers"
Free
Order from: Day Care & Child Development Council of America
1401 K Street, N.W.
Washington, D.C. 20005

This handbook talks specifically about the handicaps a young child may have. There are some broad descriptions of problems in addition to some ways of dealing with them. It is somewhat technical, but does emphasize the importance of an integrated setting for all kids.

"Directory of Resources in Manhattan for the Brain Injured and Learning Disabled"
Cost: $2.95 per copy
Order from: NYABIC/ACLD
95 Madison Avenue
New York, New York 10016

This booklet lists available resources in New York City for children with brain dysfunction and learning disabilities. Many school programs are included as a good source for beginning visits.

Committee for Community Controlled Day Care
790 Amsterdam Avenue
New York, New York

This group of people is dedicated to helping community day care centers and parents get their program going. They have lots of information about what other centers are doing for and with children. Call them!

Special Educational Instructional Materials Center (SEIMC)
400 First Avenue, 7th Floor
New York, New York 10010
686-6120, 6121

SEIMC offers free materials about education for handicapped children, films to borrow, free workshops on teaching methods, information on new materials. Call to get on their mailing list!

The Center on Human Policy
216 Ostrom Avenue
Syracuse University
Syracuse, New York 13210

This is a group of people concerned with all aspects of the lives of handicapped people. They have slides, books, booklets, as well as information on how to change attitudes in our society. Get on their mailing list.

(Free) Workshops About Children and Their Handicaps
Day Care Consultation Service, Rm. 119
Bank Street College of Education
610 West 112th Street
New York, New York 10025
(212)663-7200, extension 225

Beginning in September 1974 we now offer free-of-charge training workshops about handicapped children. These are in-service training sessions given in the community. If you put in a request, the Consultation Service will try to help you arrange workshop sessions appropriate to what your group wants to learn.

American Association for Health, Physical Education and Recreation, Unit for the Handicapped 1201 16th Street, N.W. Washington, D.C. 20036	Has information on reading materials; lists of what's available to need.
Project Quest: Films on Early Childhood and Special Education c/o Dorothy Weatherby Education Improvement Center P.O. Box 426 Pitman, New Jersey 08071	An annotated film catalog on early childhood and special education films. Ratings of films on child development, programming, management, environment, special education.
Teaching Resource Center City University of New York 144 West 125th Street New York, New York 10027 866-9430	These people offer a variety of City and State-wide resources. They will run workshops for your staff. They give out information and will help answer your questions. Call them.

Section 5

FUNDING SOURCES FOR HANDICAPPED PROGRAMS IN THE NYC AREA

I. The Federal Government, State Agencies, City Agencies and Bureaus 5.1

II. Private Foundations 5.4

III. Fund Raising on Your Own 5.5

IV. Summary 5.5

FUNDING SOURCES FOR PROGRAMS FOR YOUNG HANDICAPPED CHILDREN IN THE NYC AREA

Introduction

In this section we describe how money gets from the Federal Government into State and local agencies' hands. There is not enough money now for services for handicapped people. Pressure for more!

Funding Sources

I. The Federal Government is the primary source of funds for programs for handicapped children. In Congress, funds are appropriated for all the programs of the Department of Health, Education and Welfare each year. The programs for handicapped people are administered through the Secretary of H.E.W. in Washington.

The Federal Government gives its money in the following three forms:

1) "Formula Grants are direct Federal Grants made to designated State Agencies (e.g., the State Department of Mental Hygiene) for providing services to a specific population. The amount of the grant to the State is determined by a formula based on population, per capita income and other related factors.

2) Project Grants are awarded to public and private non-profit organizations to focus on specific areas of interest (e.g., the field of mental health.) Such grants are awarded to an organization (e.g., private agencies)

for a specific project or purpose upon completion of a prescribed application and review procedure.

3) Individuals can receive a grant by applying to the State agency designated to administer the Federal-State program; by applying to a public or private non-profit organization which has received a project grant; or by making application directly to the Federal Government."[1]

H.E.W. directs the flow of dollars to the States -- to the specific State agencies making financial requests. These State requests are in the budget, part of the entire State Plan. The State Plan describes completely how, for whom, and where the money will be used. After reviewing the Plan, the Secretary of H.E.W. arranges a "contract," an agreement, between the State Agencies and the Federal Government to provide the requested money. There is a Regional Office of H.E.W. in New York City at Federal Plaza, 10007, 264-4483, to call for information.

In Albany, the following State Agencies are in the position to contract and administer money for handicapped services from H.E.W.: the State Department of Mental Hygiene, the State Office of Education, the State Department of Social Services, and the Developmental Disabilities and Facilities Construction Council. These State Agencies

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[1] "Mental Retardation Financial Assistance Program," U.S. Dept. of Health, Education and Welfare, Secretary's Committee on Mental Retardation, Washington, D.C., July 1971, 1700-0084.

approve or reject proposals for programs on the "local" level -- for us this refers to the New York City area. If the State Agency approves a program it is budgeted, or written into the State Plan.

Some Federal and State agencies located in New York City contract for and administer money at our local City level for handicapped children's programs:

Office of the State Department of Mental Hygiene
2 World Trade Center
New York, New York 10003
488-5870

New York City Department of Social Services
80 Lafayette Street
New York, New York 10003
433-7479

New York City Agency for Child Development
240 Church Street
New York, New York 10003
553-6461, 62, 63

New York City Board of Education
110 Livingston Street
Brooklyn, New York 11201
596-8928 (This is the office of Special Education and Pupil Personnel Services which manages public school classes for special children.)

There are also City Bureaus, which can arrange contracts to get services for children from a variety of sources. They give information about existing services. They may be helpful with proposal writing, but you have to keep after them.

Bureau of Mental Health & Mental Retardation
93 Worth Street
New York, New York 10003
566-2669

Bureau for Handicapped Children
350 Broadway
New York, New York 10007
566-6000

Office for the Handicapped (Mayor's Office)
250 Broadway (14th Floor)
New York, New York 10007
566-0972

Even though these State and City bureaucracies exist, keep in mind that specific funding for programs for handicapped children is hard to get. It takes a long time to get together a group of people, to organize that group, to find out what specific applications for funds you have to fill out, and to write your proposal for the funds. But, if you are determined to get those funds from the government, then keep in mind two things: 1) it is easier to get funds if your group is already an established day care center, Head Start program, or private non-profit incorporated agency; and 2) you should contact other groups to learn what mistakes to avoid and what short-cuts exist.

Also, please call us at (212) 663-7200, extension 225, if you want help or have questions about your plans.

II. Funding Sources: Private Foundations. An alternate source of funds for programs for handicapped children could be private foundations. A foundation might pay for your program for one year while you get off the ground to demonstrate to governmental agencies that you qualify for their funds. Or, a private foundation might pay for part of your program at

the beginning, so you can get matching funds on a long-term basis from the State and City at their required percentage bases. Frankly, foundation funds to operate a program completely are very unlikely! You may try, but don't count on this source only or waste your time with them for long.

III. Fund Raising on your own is an important alternative to government funding. If your group is just beginning,you can raise your own money through bazaars, cake-sales, fairs, individual contributions and donations, monthly or yearly "dues" or "fees" for participating in the program, and other schemes you decide on. Can you charge tuition? Do you need money at all? Now is the time to think about and to discuss what your group needs!

Call us at (212) 663-7200, extension 225, to learn how other communities have managed on their own. Tell us, too, what you have discovered and learned.

IV. To summarize, funds can come from the Federal Government for programs for handicapped children. These funds are in the forms of Formula Grants, Project Grants, and Individual Grants. There are State, local and City agencies and bureaus to administer the funds and to arrange contracts for the services handicapped children need. These needs are presented to the State agencies in written proposals which then go into the New York State Plan for the Office of Health, Education and Welfare in Washington. With luck, and by adhering to the guidelines and controls the agencies

establish, it might be possible to get government funds for your program for handicapped children after a long wait and a lot of work.

While waiting, perhaps you can raise your own money from private foundations as well as from your own community via your own fund-raising projects. The government is not the only source of funds!

Section 6

IT CAN BE DONE

by Dorothy Broms

I. Real Children and Real Families -- My Recollections 6.1

II. Real Problems As I See Them Now 6.11

Dorothy Stoffer Broms is coordinator and teacher-in-charge of New York City's first class for handicapped and retarded children under its Day Care Program at Low Memorial Child Care Center in Brooklyn Heights. The innovator of "pre-trainable" classes for school age and nursery age children for the New York City Association for the Help of Retarded Children, Mrs. Broms also taught the most severely handicapped group at United Cerebral Palsy's Marble Hill Center and the nursery group at Rugby School in Brooklyn, as well as regular Day Care classes.

IT CAN BE DONE

I. Real Children and Real Families -- My Recollections

Introduction

This is a discussion of my own experiences with disabled children in both isolated and integrated settings, with a view to helping their acceptance in Head Start and Day Care classes.

Ideally, the present push toward including handicapped children in Head Start and Day Care programs should fill a huge void, both by providing classes for the under-fives and by eliminating the staggering problem of transportation altogether and by serving neighborhood populations.

Many times, in my well over twenty years as an active teacher of pre-schoolers, I have had conscious choices to make about where I could best work with the most satisfaction. For me, the most creative satisfaction has been with the children who needed me most, who could be drawn out toward the mainstream of life with extra care, skill, and attention.

I began in the City's Day Care Centers around 1950, finding increasingly that troubled and handicapped children gravitated to me, becoming my special concern. My pre-school experience merged with my involvement with handicaps born of my sister's damage from childhood illness and I started the first nursery class in one of the first special schools for retarded children in the City.

In 1960, a parent organization offered me the opportunity to set up a class for school-age children who had not been toilet trained

or socialized and were functioning too low for any existing school facility. I called the class "pre-trainable" to take away the name of "institutional training," which had implied that the children were only eligible to be trained to enter the State Institutions for the Retarded. Then, the next year a class for pre-schoolers, two and over, was successfully added because we felt that handicapped children progress best and farthest when helped as early as possible, at as young an age as possible.

Ironically, increased public interest in the education of handicapped children brought about a curtailment of the pre-school classes! The New York State Legislature, through the Greenberg Law (#4407) provided public funds for alternative education for children five years old and over who were not acceptable by the public school system. At the same time, other legislation mandated school bus transportation to alternative schools for handicapped children five and older. These two acts took services away from the very young child, since no public money, as compensation, was available at pre-school levels.

For a time, I was director of a cooperative nursery for non-handicapped children on the West Side of Manhattan. We "pioneered" with a class for two-year-olds, too. In this cooperative nursery we accepted a deeply disturbed six-year-old who was treated with tender concern by the 2 - 5 year-olds, mirroring my attitude and approach.

Later, I had a class of severely damaged cerebral palsied eight-year-olds, some of whose rights to independence had to be fought for with parents and staff before they could gain self-

reliance and a personal expectation of achievement, so wheel-chair-bound, mentally as well as physically, were they.

And now I have come full circle, back to a City-funded Day Care Center. For this third year I am conducting what began as--but happily no longer is--the only Special Class for handicapped children operating on a retarded level which is integrated into a regular day care program.

I was excited at the prospect of establishing for "my" children the same right as others have to pre-school services, suited to their own specific needs. I envisioned the gradual spread of these classes until all who needed them were served. Handicapped children and their parents have an urgent need for skilled trainers and guidance as early as they can be brought to it, so that every bit of their potential may be utilized, and no additional crippling by pity-spoiling and lack of expectation takes place!

It is so rewarding to work with these children! They come to one so closed in, fearful, unwilling to adventure, and they bloom so beautifully with careful, loving, skilled attention. Let me introduce you to some of them. Perhaps they can best speak for themselves:

About the Children and Families

How vividly I can call up my first class nearly 20 years ago! Shy little blond Ralph, a tiny Downs Syndrome child with slanted eyes and loose-jointed body, who would throw both arms and legs around my neck in gay welcome; Denny with large head and stumbling gait, who needed love endlessly, because he had never had it, as he was shunted from one foster home to another. Terrified of the

bathroom which apparently had become for him a place of trouble and punishment, he had to be cajoled into "visiting" it for many days before he could be calm enough to understand its uses. He spoke his first words in the tension-dispelling rhythm of swinging on the swing to the chanting of the teacher.

And then there was Lyle, who slid under a chair when I looked at him, and always slithered away from everything. A moment of great triumph that I still can feel came 6 months later when he suddenly responded to his name called across the room, and came over to me without being brought.

I hear again the little five-year-old twin Downs Syndrome brothers who seemed to have no speech or understanding of it, as I heard them one day in the playhouse chattering away to each other in a language of their own.

There was Mike, a tiny, pale four-year-old with wobbly legs and trembling hands. He could do nothing for himself--go to the toilet, eat, take off his coat. His reaction to any failure was complete retreat, big tears welling up and silently over-flowing. When he tried to hold a cup and a few drops spilled, he would become terrified. For toileting, he made no attempt to pull down his own pants, or even to indicate need.

But going to the bathroom with one or two other boys as a "social" activity broke down his anxiety, and he was very soon able to take satisfaction in the toilet "like a big boy." And how great his triumph when he succeeded in taking off his coat, carrying his own plate, doing an errand. Gradually, over the months, he became my most competent child, able to carry things, pass dishes at the table, take care of his own toilet needs independently, even help

other children. He began to speak, too, as he gained a feeling of himself as someone with needs to express. And most gratifying of all, he actually gained the strength and zest to be mischievous--to tease and shout and play wildly. He had been helped and protected almost to his own extinction, till he felt himself utterly incapable. And, while he was a retarded child, undoubtedly, he was one who could learn to help himself and others.

Vicky appeared much more retarded than she really was when she came to us because she went wildly from one thing to another, whims flashed across her attention and became imperious needs; a constant jabbering flow of sounds impeded any real effort at speech.

Vicky's parents were pathetically eager for guidance. They sat up with her many weary hours at night because she would not stay put in her bed. They were afraid to cross her in anything, or insist on any discipline or performance from her. They were the victims of a mechanical doctor, who, after having operated on the child's body for congenital malformations, thought of her only as a physical machine that must be kept undisturbed, warning the parents "not to upset her," and made no provision for the restless little spirit within which needed training and strong direction to help it grow.

We helped Vicky by establishing a routine, by insisting on her constant, consistent conformity, to rivet her attention on the fact that she had to accept direction. This routine, at times severe, has produced a quieter, happier, more alert girl. She learned, like her two sisters, to settle down at night. And most especially it has proved to the mother that Vicky is not fragile, not breakable; that she can must be <u>treated like a child, not a pet</u>! The parents now have quiet evenings to themselves, too.

Or take Carole--a charmer, with round eyes and utterly captivating smile, who whined, wailed and hit herself on the head, looking at you sideways to see your resistance crumble. One day I finally offered to do it for her, and she looked at me amazed, dropped her hand and opened her mouth to howl, then slowly closed it, picked up her spoon and fed herself. (She had wanted me to do that!)

She is wobbly in her gait, having been born with a mild, congenital dislocation of the hips, and she insisted on being helped constantly. It is a joy to see her now push her chair away from the table and wriggle down, and head out for the bathroom, or a game, with firm, if spraddled gait--not waiting for a helping hand--(not offered). When a whine does not bring her a helping of food, she will say what she wants. Carried away by the fun of a game, she will call out the words. Because her family could not bear to see her cry, did not have the heart to force anything, they were tenderheartedly producing an utterly dependent person instead of the gay and gallant little trouper hidden within Carole.

One day a man from India visited our center to get help in starting one where his own child could be taught. His child was born with Down's Syndrome, or "Mongolism," and he had heard that such children could absorb a good amount of training to become charming and happy participants in a family or classroom group. As they became adults, they could even hold down certain jobs for pay. Just as other children are given the opportunity to develop, he hoped to have his own child develop to his utmost capacity. He explained that educating handicapped children was a problem new to his generation of city dwellers in India. Until the present, people had lived in family groups rather than in small city apartments, and each family group cared for its own dependent members.

Yet in our own country, these children, until the recent past (and sometimes even today) were automatically recommended to institutionalization in infancy so that the family might never feel them part of it. And by this, many were deprived of the chance to develop as they might have, and instead, only vegetated, or died.

Ten years ago, when I conducted a Workshop for parents of retarded infants, one mother, Mary Stock, told me what happened when her little daughter, Pamela, then 3, was born:

She related, "I saw Pam as soon as she was born, was happy to see a chubby little girl, about whom I remarked, 'looked kind of Oriental'.

"But the next day when the nurses brought the babies to the other mothers in my hospital room, they didn't bring mine. When I asked why, I was told only that 'Your doctor will talk to you.' He came in finally, drew the curtains ominously around my bed and told me, 'You have a Mongoloid; you would do better not to take her home--for the sake of the other children, the whole family.'

"Now I had been through college, studied psychology, but the term 'Mongolian Idiot' leaped into my mind--I pictured a blob--a perpetual infant, sitting forever in a high chair, untrainable, incontinent--I really knew nothing about it.'

"And neither did he," she interjected parenthetically, "if he could see her now--what a darling she is, and what a joy to us."

"This happened on Saturday and I was to go home Tuesday--what was I to do? What a short time! This was my child whom I had carried all those months! Where would I send her--what did you do with 'them'?

"But I was fortunate--I had a pediatrician who came hurrying in--

though it was a holiday--to see me when he heard about Pam. 'Mrs. Stock,' he said, 'You had planned to breast feed your baby--you waited so eagerly--take her home and try--give her a few months with your family--then see if you need to place her' (in an institution).

"That was all I needed--what mother wouldn't take her baby home--no matter what--*if given any encouragement*?

"And she was a sweet baby. She needed more care, more teaching, but she tried hard from the beginning to please me, and I, expecting so little from her, was able to be excited by her *progress*, slow, yes, but steady.

"I have her now in a nursery school with normal children a bit younger. She's almost four and she holds her own pretty well.

"She is sweet and affectionate and responsive, and the chief danger she faces is being too spoiled by her father and brothers--for she's our only girl! My heart stops at the thought *we were almost persuaded not to think of her as a person*!

"That obstetrician--he was just a baby producing machine--my husband and I weren't even people to him--just a failure."

Thoughtfully, she added, "I told him so when I had Freddie last year, how we loved and cherished Pam. I don't know if he even learned by it--I hope so."

"Another couple who sat with us at a parents' meeting have a Down's Syndrome boy Pam's age. They weren't so lucky. Their doctor didn't let them think, and they didn't have any confidence to believe that they had any choice but to 'put the child away.' He was sent to a small infant hospital while on the waiting list for one of the big state institutions. Then he was accepted there. The mother was

heartbroken to see him regress. Before he left the small nursery, Sam had been standing up and walking around in his crib. Now at 18 months, in the institution he was almost completely supine and responseless. Finally, Mrs. Smith was buttressed by advice from a Clinic parents' group. She took him home at age 18 months, and he tested at a 6 months level. After about a year of home care and love, he was tested again and had progressed to an 18 months' level. Sam thrived, obviously, in the loving home where he was encouraged."

Just as normal babies being cared for in hospitals and institutions demonstrate a great lag in development, deprived of that essential ingredient of personal and loving care, so also do handicapped children relegated to institutions.

Surely the necessities of other family members can be adjusted to the needs of the handicapped infant, as they would have to be for the expected normal infant, for at least those first few precious years of family life so necessary to the future development of any human being!

Do, I beg you, listen to Mary Stock's baby doctor--"Take him home and try!"

All children, no matter how handicapped or retarded, have some potential, some level of response and enjoyment and self-responsibility they can be helped to reach. They are entitled to that future of hope and promise. All children are <u>children</u> first, entitled to love and training and discipline, so that, on whatever level, they may fulfill their utmost capacity as citizens of the world, not reject material, to be put aside and as nearly as possible, forgotten!

Interlude

Now that you have read about some of the children we have been familiar with, many of you are thinking about having children in your center who are like them.

And there are many of you who have decided that you are in no way either ready, willing, or able to take children who have disabilities--either mild or severe.

For those of you in both these situations, please read this next part which is Mrs. Broms' report of some ways to look at the current picture for handicapped people in our country. Perhaps, after you read this, you will realize the role you can have in changing the current picture. It will not be easy for many of you to take the necessary stand to include those handicapped kids in your center. Nor will it be easy to keep them there in the kind of program you feel they will benefit from. It will be necessary to fight like hell for everything you feel is right, because the bureaucratic and political conflicts that exist where programs for handicapped people are concerned are enormous.

We hope this next part will help you figure out why, to raise questions about how programs fail to do what they could, to perhaps provide an answer for your group to some of the frequently depressing aspects of planning a good program for young handicapped children. We hope that you will be moved to action--taking into your center some kids from your neighborhood with handicaps!

II. Real Problems As I See Them Now

Past and Present are Tied Together

It's a strange, ironic thing to contemplate.

In my generation, fifty years ago when my sister was smitten with encephalitis, there were no resources to help her, other than what our parents, determined to restore her as fully as possible to a place in life, could devise for her. Nurses, tutors, extension courses all played their part in pulling her up to her intellectual potential; but the isolated, over protected life they saw no alternative to has left her severely handicapped by inadequate life experience, a hopelessly dependent person.

The last quarter of a century has seen a strong movement of parents of all sorts of handicapped children, banding together to demand and force recognition and help for their children, and to repudiate the rejection and stigma traditionally attached to imperfect people in our society. Much has been accomplished by these organizations. Pilot classes for very handicapped children have proved that they could be trained and educated to lead worthwhile satisfying lives, often making small contributions to society in addition to caring for their own needs.

Yet, just this Spring, I actually heard representatives of organizations set up to help handicapped children tell a meeting called to facilitate integration of these children into Headstart classes that they would not really want to accept them--they were physically disagreeable and uninviting, would alienate parents and staff, and "disadvantage" the normal children in the groups. One

representative told an anecdote of suspending too-successful toilet training because it almost caused a family to decide to keep their child in the home instead of institutionalizing it as the "expert" recommended!

I have been in the field for over twenty years, exposed to it for half a hundred, hoped and sometimes could believe significant changes in understanding and attitude had taken place.

Yet, last month from the parents of a Mongoloid boy functioning close to his four-year-old age level I heard again the dismal story. They had been advised by the attending physician at birth not to take this boy home, not to admit him to their family of three other boys, "to put him away and forget him."

Ironically, Mongoloids are among the most trainable, easily assimilated and sweetest children on earth. I once refused to start a showcase class of "only darling little Mongoloids" when propositioned to select only those children for an initial venture in integration who would ingratiate themselves easily with the normal population. My mixed class of "handicapped children operating on a handicapped level," holds a real cross-section of functioning levels and disabilities, including cerebral palsy, brain damage, Down's Syndrome, hydrocephalism, emotional disturbance and autism has had as its criteria for acceptance any child who needs basic help and training before he can be accepted in any other facility.

The present "system" of service for handicapped young children is pure anarchy.

We find in the great City of New York no consistency, either of counselling, referral or even diagnosis.

Parents are left to fumble and blunder their way through an uncharted wilderness, sometimes applying at four or five places before finding service for their child.

I have come to think of the term "Battered Parent Syndrome" to describe the state of desperation and bewilderment in which many parents finally arrive at our school.

Because we accept children no one else will take, try to see them immediately upon application and provide them at once with some kind of service, we are often the port of last resort. If a child is too old or too-high-functioning for us (the only reasons for refusal), we try to find a place to send the family on to, not to cut them adrift again.

But even in our center, composed of three day care classes for three-, four-and five-year-olds, and my special class for handicapped children operating on a retarded level, I experience profound frustration when faced with the problem of placing in a regular class a child beginning to be able to benefit by such company. This child needs the stimulation, but also still needs extra awareness and attention from a special teacher. There is no provision in our staffing for a transition teacher* for a short period to smooth the change for a child or for an extra, trained person to make it possible for the hard pressed staff of the regular classes to absorb this child into its group.

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* The only school I have heard of having this luxurious necessity is the Gateway School in New York City which places children when ready in Public School with the transition teacher to smooth the way.

We do have one exception, a very bright three-year-old suffering from Spinal Bifida, a condition which makes toilet training almost impossible, but who would be completely incongruous in a retarded group. He is brought to our special classroom for changing at regular intervals, and could not have been accepted into the regular room otherwise. Then, too, I have been counselling both the staff of his class and his parents in the special problems that arise. Another child in the three-year-old class has a deeply withdrawn autistic sister in my group, and his teacher and I have cooperated in interpreting to his group his sister's bizarre behavior and lack of speech. These threes are growing up compassionate and accepting of deviations from the norm.

The children in my special class carry school bags to school everyday, containing, as with other children, the essentials for their school day. In their case it is a change of clothing (and the wet ones at night, if we are still working on toilet training), and, in several special cases, special foods the child's condition requires; or a particular comforting toy or blanket; notes back and forth or the child's paintings.

As quickly as may be, we remove the unnecessary differences between our children and the outside world, and try to make the necessary ones explicable and thereby acceptable to the normal world we strive to make them a part of.

These are lovely children, winning children. My answer to anyone who views with trepidation their acceptance into normal settings is a warm invitation to visit my class. I have yet to have a visitor go away without expressing involvement and affection for the children.

Sometimes surprise, yes, but not rejection--just a startled realization of the essential sameness of my children to all children, once really seen and understood.

I really believe it adds an extra dimension to the character and understanding of young children to give them the opportunity to know and love and accept all other children, whatever their differences or disabilities. The attitudes of the adults of the school are mirrored naturally by the children and even carried along to the parents. Most handicaps can be adjusted to, compensated for, lived with, if the key factors of acceptance and expectation, learning and growing are present. But the climate for learning and growing is all important. Both within the family and the community there must be warmth and welcome, and this can only come from familiarity and from integrating, as much as is possible, into the regular activities within the community.

Let Me Sound A Warning!

There is a danger in accepting uncritically the government's program to include handicapped children in its HeadStart and day care centers for normal children. In the eager hope that all our children will at last be recognized and provided for as an integral part of the early childhood population, we must not allow special provisions, special expertise and training to be ploughed under. This can happen all too easily.

For example, this year, in my own initial joy at the prospect of doors of all centers being opened to "my children" and responding wholeheartedly to a request to help facilitate this, I brushed aside the trepidation of teachers who had no previous acquaintance with the problems of the handicapped.

But then I began to examine the very real difficulties that have blocked the flow of handicapped children from my class to our center's own regular classes and realized that the same difficulties in more aggravated form faced HeadStart and day care centers asked to absorb handicapped children. Their staffs had no special training in meeting these needs, or additional hands (even non-specialist ones) to provide the vital extra degree of attention needed both to the handicapped child and to the adjustment and understanding of his classmates to his specific needs, that are the sine qua non of success in this venture.

The only recognition that special problems may arise is the ridiculous sop of $100 per child per year "extra" for handicapped children in the HeadStart classes. This would not even provide an hour a day of any kind of extra help, let alone the consultative services, special equipment, etc., without which workshops and meetings alone are virtually useless.

I have spoken at conferences to staffs of HeadStart programs who were immensely uneasy at the prospect of plunging into work with children whose special problems they had no familiarity with and I thought by my warm account of the rewards of working with these children I could persuade them to try.

But I began to realize that without some actual, on-site assistance at the onset, my accounts might instead discourage inexperienced people. In an effort to offset this, we offer visits to our center, with as much on-the-job training as staffs can be spared for.

However, it really serves to highlight the complete inadequacy and superficiality of the "Mandate" to take the children in <u>every</u>

center. For not only is it completely impossible for our small setting to absorb even the visitors we now get and give them any meaningful training; but this is a completely unauthorized, unplanned, individual finger-in-the-dyke effort, and even for this, it is suggested we are spreading ourselves too thin.

But how can we do otherwise until there is the organized effort to make the new provisions work? Until there is the training and buttressing help that can offer some hope of success? Until there is adequate money to do a good job? Until there is some real thought about and recognition of children's needs?

The "Mandate" must not be cynically used to syphon off children in need of special services into holding operations that are not equipped even to contain them, so that numbers can be added to reports, and it can look on paper, as though our handicapped children's problems are being met.

This situation is exacerbated by the recent release* of yet another report from the President's Committee on Mental Retardation headlined "Panel Calls for More Effort to Better Lives of Retarded." This stated that one-third of the retarded persons now institutionalized could return to the community and lead useful, productive lives.

"The answer is not just removal from the institutions," the committee said, "but a concerted effort of a variety of community services that can provide good alternatives to institutional living--or a bypass of the institution altogether."

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* St. Paul Pioneer Press, August 14, 1973

But the report admitted that resources for such programs as they recommend--in six pretentious, high sounding steps, redundant with words like "establish", "intensify", "improve","fullest use", must be called "skimpy" and quality services both for prevention and treatment are reaching only a small percentage of the retarded population.* At fault, the committee charges, are spotty funding, backward methods and lack of a "national pattern" to tackle the problem.

"Helping the retarded takes adequate staffing by trained professionals and paraprofessionals," the committee said, and "the desire to help them. We no longer have the excuse of not knowing how."

The evidence that such an effort will actually take place--if left to existing governmental and social agencies--is scant, if we look at the past years' record of sharp cutbacks in funds and even closing down of facilities for the retarded and the otherwise handicapped children.

Many parents of intitutionalized children, horrified by the Willowbrooks in our society, along with an increasing number of workers in the field of handicapped children, are beginning to seek viable alternatives. In this involvement by those most directly concerned with the care and treatment of children lies the only real hope for fundamental solutions to the problems of retardation and other handicaps.

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* How "skimpy" the resources are is illustrated by the fact that "not more than 60 per cent of retarded children are being served in any state," with only a few states, including Connecticut, Wisconsin and Pennsylvania, moving more than one-third of the institutionalized into the community.

We can't afford to be duped by mealy-mouthed promises any longer, while our children stagnate and lose their chance at life.

We can grab hold of the promise and force it to become fact.

Let's insist on help and training from specialists; let's demand adequate staff additions; let's blast a hole in the weary cynicism of Federal reports that give answers with one hand only to snatch them away with regretful admissions of "skimpy" resources, by the other.

They no longer, they confess, have the excuse of not knowing how. Now we must force them to use that know-how! You and your center can perhaps be a part of that force which will make new and adequate programs happen.

A Grim Timetable

1960's

The scandalous "revelations" of conditions at Willowbrook and other institutions in the past year (1972-73) have brought about a flurry of concern and promises of remedial action upon the part of public officials and legislators. But a similar--and also highly publicized "revelation" in the 1960's by the late Senator Robert Kennedy and other politicians of essentially the same inhumane conditions and lack of proper care for the mentally retarded--brought about a like amount of pledges of reform, soon forgotten.

1969

Four years ago (AP dispatch from Washington, D.C., April 22, 1969), it was reported at a Senate Labor and Education Committee hearing that only 2 out of $5\frac{1}{2}$ million handicapped children requiring special education services were actually receiving them. At the same hearing, it was also revealed that there were only 75- to 80- thousand teachers and specialists to work with handicapped children, when the actual need was for 300 thousand such workers and specialists. Still woefully unfulfilled.

1973

Now, a report from the President's Committee on Mental Retardation (a Federal agency dating back to the 1960s) has recommended six steps to achieve the following goals:

Reduction by half in the occurrence of mental retardation.

Return of one-third of those now institutionalized to the community, where they can live useful and productive lives.

The Committee claims to know how to meet the goal of "successfully returning to the community at least one-third of the more than 200,000 retarded children and adults now in public institutions." (UPI, August 14, 1973) With only words, no money.

1975 ?

This Section written and contributed to this Handbook by Dorothy Broms, November, 1973.